

**Department of Health and Human Services
National Institute of Environmental Health Sciences
National Cancer Institute**

**Minutes of the Research Translation, Dissemination, and Policy Implications
Subcommittee of the Interagency Breast Cancer and Environmental Research
Coordinating Committee**

April 15, 2011

The Research Translation, Dissemination, and Policy Implications (RTDPI) Subcommittee of the Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) was convened for a meeting on April 15, 2011 at 1:00 p.m. via conference call. The Chair of the subcommittee was Jeanne Rizzo, R.N. of the Breast Cancer Fund.

Subcommittee Members Present

Beverly Canin
Ronda Henry-Tillman, MD
Karen Miller
Marcus Plescia, MD, MPH
Jeanne Rizzo, RN
Sheila Zahm, ScD

NIH Staff Present

Laura McGuinn, MPH (NCI)
Liam O’Fallon, MA (NIEHS)
Mary Gant (NIEHS)

CDC Staff Present

Galen Cole, PhD, MPH

I. BACKGROUND

The Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) is a congressionally mandated body established by the National Institute of Environmental Health Sciences (NIEHS), in collaboration with the National Cancer Institute (NCI). This Committee is comprised of 19 voting members, including representatives of Federal agencies; non-federal scientists, physicians, and other health professionals from clinical, basic, and public health sciences; and advocates for individuals with breast cancer.

The Committee's primary mission is to facilitate the efficient and effective exchange of information on breast cancer research activities among the member agencies, and to advise the NIH and other Federal agencies in the solicitation of proposals for collaborative, multidisciplinary research, including proposals to further evaluate environmental and genomic factors that may be related to the etiology of breast cancer. The Committee serves as a forum and

assists in increasing public understanding of the member agencies' activities, programs, policies, and research, and in bringing important matters of interest forward for discussion.

The objectives of the RTDPI Subcommittee of the IBCERCC are integrated and dependent on the objectives and activities of the other Subcommittees¹ of the IBCERCC and include the following: to identify successful models as well as gaps in research translation and dissemination, to make recommendations to improve both with an emphasis on breast cancer and the environment; to make policy recommendations to that end; to address areas in which the scientific evidence on breast cancer and the environment supports precautionary public health policy; and to identify methods to expand public participation in the research translation and dissemination processes to more effectively involve patient advocacy and community organizations, environmental health, environmental justice as well as practitioners in public health and health care delivery.

The third meeting (conference call) of the RTDPI Subcommittee took place on April 15, 2011. During this meeting, progress from each of the initial work teams was discussed. The minutes from the March meeting were reviewed and each of the teams' goals were discussed along with action items.

II. DISCUSSION

Minutes

Jeanne advised that RTDPI members review the minutes from the other two IBCERCC Subcommittees, as their work may inform the work of the RTDPI Subcommittee. An overview of the State-of-the-Science and Research Process Subcommittee's progress was provided. It was suggested that if anyone has questions for other Subcommittees, or global IBCERCC questions, to email Jeanne and she'll pass them on and get back to the RTDPI Subcommittee members.

The minutes from the March RTDPI meeting were reviewed and the action items from that meeting were discussed. For those members that are not comfortable with SharePoint, they were encouraged to speak with NIH staff. Members inquired about the nominations timeline for a new RTDPI member to replace Alice Chang.

Members discussed what to do with list of risk communication experts. Members decided they would review the list of risk communication experts and decide how the experts could advise them if they needed help.

Subcommittee Work Teams

Review of goals and progress on outlines:

1) Group A: Patient Advocacy - Beverly, Karen, and Ronda

Goal #1, Identify successful models and gaps in research translation and dissemination.

¹ The other Subcommittees of the IBCERCC are the Research Process Subcommittee (Chair, Michael Gould) and the State of the Science Subcommittee (Chair, Michele Forman).

Beverly followed up on the literature recommendations made by Gwen². Beverly would review books and contact authors to inquire about recommendations from their books. Beverly would also go back and pick out most relevant issues from the books. Karen discussed the interview process and that the interviews are completed.

There was a group discussion on when to communicate results from research studies to the public. There is a gap in the communication between scientists and advocate communities during the study process. It was mentioned that audiences need to be identified and polled on how to receive and when to receive results. Members thought that there was a gap in timing of when researchers receive the results and when the findings are communicated to advocates and the general population. Marcus commented on how to talk about communication of the results without causing public panic.

Sheila and Mary discussed that scientists in the government produce data, they don't make policy recommendations that advocates would be making. They discussed that scientists publish the results from their studies in peer reviewed journals and NTP Tech Reports and then regulatory agencies and the general public can pick up these documents and use them for decision making. Jeanne commented that the public wants something more than a journal report.

Jeanne recommended that grant proposals need the request for resources to include funding to communicate findings. This is not typically in the grant proposal. The group agreed that risk communicators should be brought in at the very beginning to see the progress from the start of the project.

Beverly discussed goals for the Team 1: main chapter headings would be ready by next meeting on May 2nd.

2) Group B: Policy & Communications - Marcus, Sheila, and Jeanne

Goal 4: Make recommendations for precautionary public health policy supported by scientific evidence.

Group concurred with the main findings and recommendations from the President's Cancer Panel Report³ and the National Conversation on Public Health and Chemical Exposures Summary of Recommendations. The group stated the reports are broad and they agreed that this is a good approach for any environment and health issue.

President's Cancer Panel Report

- It was recommended that the precautionary principle approach should replace the current reactionary approach. This should be pulled out from the articles and reiterated because this point is important. The group agreed on this stance.

² Reviewed books: *Hyping Health Risks: Environmental Hazards in Daily Life and the Science of Epidemiology* by Geoffrey Kabat, *No Family History: The Environmental Links to Breast Cancer* by Sabrina McCormick, and *From Pink to Green: Disease Prevention and the Environmental Breast Cancer Movement* by Barbara Ley.

³ <http://deainfo.nci.nih.gov/advisory/pcp/annualReports/index.htm>

- The topic of radiation exposure was discussed. Sheila stated that CT scans are increasing particularly among children when developing girls are more vulnerable to insult. Marcus commented that this may be something that needs more immediate action.
- There was a discussion on the role and of the RTDPI Subcommittee. Members discussed that the Subcommittee does not need to make recommendations for science, rather its purpose is to make recommendations on policy implications of the science. The scope of the RTDPI Subcommittee was also defined.
- Marcus stated that in addition to concurring with entire report, it's important to pull a couple things out that the group wants to reiterate.
- It was recommended that the group should take a look at reports and send Jeanne comments. If the members don't feel as though there is enough research, they should send comments to Jeanne and she will bring it up with the State of the Science Subcommittee.

The Pathways to Breast Cancer: A Case Study for Innovation in Chemical Safety Evaluation⁴ report was discussed. This report is useful because it calls for looking at things other than known mutagens and carcinogens.

National Conversation on Public Health and Chemical Exposures

Marcus discussed that the first three sections remain to the other groups and that sections 4 and 5 are what the RTDPI Subcommittee should discuss. The members concurred that all of the recommendations were broad and that it might be useful to emphasize specific things, such as:

- 4.6: We need to engage communities in health projects and we need to work to provide more training for federal agencies to be able to accomplish this.
- 5.1: Deciding on the best way to communicate and disseminate information.
- 5.2: Right to know about ingredients
 - We are entitled to this information unless someone can prove why we shouldn't have access to it
- 5.4: Public should have knowledge of chemical exposures and health
- 5.5: Increasing public access to data
- 6.1: Important because it discusses how to establish environmental health competencies and how to translate and disseminate new research so providers can get it and know how to take information to work with it.
 - Ronda discussed that many doctors don't assess environmental exposures because it doesn't change the outcome in what they are doing. Marcus commented that many practitioners don't understand how to assess harm from chemical exposures.
- 6.4: Strengthening capacity – developing clinical practice guidelines for addressing chemical exposures.

Confidential business information comes up in a number of sections (5.4, 5.5). Refer back to the Research Process Subcommittee. Jeanne will pass that information on to Michael Gould. Jeanne also brought up the Declaration of Asturias⁵, which other members felt was important because it

⁴ www.sehn.org/pdf/BCCP%20report%20FINAL..pdf

⁵ <http://www.iarc.fr/en/media-centre/iarcnews/2011/asturiasdeclaration.php>

shows that the precautionary principle is growing and that the WHO is taking action on the precautionary principle.

Marcus will flesh out outline for this team. Sheila will work on section about precaution and hazard and risk assessment. Sheila will send first draft to Jeanne and Marcus.

Goals 5 & 6: Communications

Guest advisor, Galen Cole, Associate Director Communications CDC

- Galen recommended that communicators should be brought early on in the research process.
- Galen advised that you need to know who you are going to communicate with, when they need the information, what form they need it, what are the messages, and whether these messages are going to work with the audiences they are trying to reach.
- Galen discussed developing an IBCERCC communication tool-kit adapted from dealing with cancer clusters.
 - Formulate the scope of their responsibility
 - Decide who would be doing the communicating
- Marcus recommended that any researchers that engage in environmental causes of breast cancer should have a communication plan in place. Beverly agreed with this, suggesting that specific elements of the plan should be noted.
- Galen said he would frame recommendations for the tool-kit to move process forward.
- Liam mentioned the BCERP key messages and was going to check and get back to the RTDPI Subcommittee.

Action Items:

- Before May 2nd the RTDPI Subcommittee will share with each other chapter heading outlines for the various sections. This way, by May 2nd people can view and tweak the headings with questions and suggestions.
- Members are to send global IBCERCC questions, or specific questions for other Subcommittees, to Jeanne and she will provide feedback to the group.
- The committee concurs with the President's Cancer Panel and the National Conversation on Public Health and Chemical Exposures reports
 - The committee needs to pull out a handful of specific recommendations that they thought were important and then have a narrative about each of them.
- Members should review documents posted to the SharePoint⁶:
 - The Environmental Information Initiative, the Toxic Substances Control Act reform bill (Safe Chemicals Act of 2011), the President's Cancer Panel & National Conversation on Public Health and Chemical Exposures Summary of Policy Recommendations, etc.
- Review what Sheila sent and work together to come up with the piece that Sheila is doing
- Galen is going to work on overarching communication piece and toolkit plan.
- Ronda, Beverly, and Karen will work on team one deliverables.
- All members should review minutes from other IBCERCC Subcommittees.

⁶ <http://sharepoint.niehs.nih.gov/IBCERCC/CommitteeMain/TranslationDisseminationPolicy/default.aspx>

- SharePoint: If anyone is still having trouble with SharePoint contact NIH staff

III. ADJOURNMENT

The meeting adjourned at 3:55 p.m. on April 15, 2011.

CERTIFICATION

I hereby certify that, to the best of my knowledge, the foregoing minutes and attachments are accurate and complete.

/Jeanne Rizzo/

Jeanne Rizzo, RN

Chairperson

Research Translation, Dissemination, and Policy Implications Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

/Gwen W. Collman/

Gwen W. Collman, PhD

Executive Secretary

Research Process Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

Proper signatures

Treat as signed, § 1.4(d)(2)